

Building Positive Approaches To the Chronically Ill

UNDER THE TITLE, "Building Positive Approaches to the Chronically Ill," a symposium on the problems of the persons, both professional and nonprofessional, concerned with helping the patient with chronic illness was sponsored by the American Cancer Society at the National Conference of Social Work in June 1953.

Opening the discussions, the chairman, Caroline H. Elledge, M.A., associate professor of social work, University of Denver School of Social Work, quoted this statement from the advance notice describing the symposium: "Constructive adjustment by the patient to permanent physical handicaps and disabilities, as well as to the conditions of degenerative disease, depends to a large extent on the attitudes of those who are close to him and to whom he looks for help." She pointed out that the very use of certain words and phrases, such as "victim of," "devastated by," and "dread disease," have emotional implications which play into the negative rather than the positive feelings persons may have about patients with permanent physical handicaps and chronic illnesses, and she considered this a matter for grave contemplation.

To set the stage for general discussion, a panel of five outlined the problems of the medical team—the medical social worker, the nurse, and the physician—the public assistance worker, and the volunteer in their attempts to meet the needs of chronically ill persons. Presented here, in brief, are the remarks of four members of the panel. The paper by the fifth member, John L. Caughey, Jr., M.D., associate dean of the Western Reserve University School of Medicine, Cleveland, Ohio, was available only in abstract form.

In discussing the physician's obligations, Dr. Caughey emphasized the fact that the very human tendency on the part of the physician to feel frustrated in the chronic disease situation is accentuated by his training in medical school. "The relationships the students have with individual sick persons usually occur during some relatively dramatic acute illness or during the exciting diagnostic phase," he stated. "In neither of these situations is the student helped to learn the true nature of the patient-physician relationship or the role of the physician with the chronically ill patient where the diagnosis is obvious, the therapeutic possibilities limited, and the course prolonged."

The Social Worker



Within the definition for chronic illness, "a prolonged disease process which usually has a gradual beginning and leaves traces of permanent injury to the body even when treatment has been effective," there are many variations which must be considered when talking about positive

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approaches to the chronically ill. The "prolonged process" may be a matter of weeks or of years. The "gradual beginning" may also involve more or less time and have varying degrees of symptom manifestation. The "permanent injury" may be slight, or it may constitute complete or partial loss or impairment of body parts, essential functions, or capacities.

In my remarks, I shall be referring exclusively to chronic disease situations in which severe physical or mental disablement still cannot be prevented or avoided even with a combination of the medical, psychiatric, and social knowledge of today. At Memorial Center for Cancer and Allied Diseases in New York City, I worked with the parents of children who had leukemia, an invariably fatal chronic illness, the duration of which averaged between 1 and 2 years. This is an atypical chronic disease situation; yet, frequently, it is from the extremes of experience that generally applicable principles can most easily be found.

In this work at Memorial Center, we discovered that goals of case service could be plotted only on a negative scale. It was possible to help mothers accept and live with the constantly present shadow of death. It was important to participate in the effort to make the experience no more crippling emotionally for parents than it was by definition. But the caseworker could do nothing to change the essentially irreversible nature of the illness.

In such a situation, casework supervisors have a large task in helping workers to handle their own human reactions to tragedy and to find the truly professional role they have to play in helping mitigate the effects of the circumstances, even though they cannot change the circumstances themselves. There are two aids to supervision which I think may be needed in many chronic disease hospitals, wards, or services. The first of these I shall call personnel management; the other, compensation for limited case goals by broadening professional goals.

Personnel Management

Personnel management, in its simplest terms, consists of defining a working condition which

reduces the productive capacity of a number of workers and doing something about it so that productive capacity of a majority of the workers will be restored. If a certain kind of noise reduces the productive capacity of one worker, it is a matter for supervision. If that kind of noise reduces the productive capacity of a number of workers, it is a problem for personnel management. In social work, we are conscious of the "noise factor" for individual workers, but I wonder if we have effectively interpreted the degree to which one worker's reactions may be representative of many workers' reactions. A worker who becomes frustrated and depressed with a caseload of patients who have had radical head and neck surgery and loss or impairment of speech is not necessarily peculiar. Nor is a worker necessarily neurotic who finds difficult a caseload weighted heavily with terminal illnesses.

We must find and define those areas which involve consistently massive emotional impact for most workers. There may be some services to which no worker should be assigned for more than 6 months. We may believe that continuity of social casework service is best achieved by one worker continuing indefinitely on the same service. But this is an idle dream if the "average" worker is unable to tolerate the stress indefinitely. We had better depend upon the "average" worker and establish definite policies for staff rotation to cover the high-pressure areas. It would be far better to permit a worker to continue beyond the rotation period if she is able to and willing to tolerate the stress longer than the hypothetical average worker than to transfer a worker off the service "because she couldn't make the adjustment." On some traditionally 1-worker services it may be better to use half of 2 workers' time than all of 1 worker's time. In this way, excessive pressures may be diluted and the workers given an opportunity to share their experiences in order to reduce the impact.

Sick leave policies should perhaps also be adapted for workers in some of the high-pressure situations. When professional capacity to help terminally ill patients and their families is occasionally paralyzed by a worker's accumulation of feeling, is the worker ill? Whether this is illness or not, temporary escape may be

essential for this worker in order for her to regain her professional capacity. A worker must be helped, through supervision, to use mechanisms other than escape, but even skillful supervision cannot always meet a worker's occasional need to be a million miles away, to forget and deny that human beings are so severely attacked by disease.

Broadening Professional Goals

As compensation for limited case goals, professional goals of social caseworkers can be broadened in two directions: in the development of total community services, and in research.

The social worker who is concerned with chronic illness has the opportunity to see some of the most glaring community needs—home care programs, more facilities for treatment, work and recreation programs for the aged chronically ill, appropriate noninstitutional housing, resources for handicapped children, psychiatric facilities, and vocational rehabilitation programs, for example. The social worker knows, or can know, from daily experience what is needed and why. She has the heart of interpretive material at her finger tips. The time has come to interpret the role of the worker in a chronic disease situation not only in terms of social casework service, but also in terms of responsibility and opportunity to aid in community planning.

There are several ways in which social caseworkers may contribute to research, but here I am most concerned with the development in social service departments of an accepted, inherent function of aiding in the formulation of researchable theory. The social caseworker in a chronic disease situation has an opportunity to observe the reactions of patients before and after surgery—of patients who live daily with the idea of impending death, of patients whose disease has meant radical alteration in living patterns or in physical and emotional functioning. Few people are as well equipped as social workers to find in their daily practice clues to the possible relationships between given diseases and treatment processes and social and emotional phenomena.

For example, the social caseworker on the gynecology service and the social caseworker

on the breast service at Memorial Center for Cancer and Allied Diseases in New York City, in informal comparisons of their work, arrived at the impression that women who had had hysterectomies experienced, or at least demonstrated, less emotional trauma than did women who had had radical mastectomies. This is an interesting impression. So interesting, in fact, that one is tempted not just to formulate theories as to why, but to jump to conclusions. Before social workers can permit themselves the luxury of theorizing, however, they must permit themselves to be subjected to a certain amount of scientific discipline. In this situation, there are at least two questions which must be asked. The first is relatively simple: What are the gross comparisons between the patients on these two services and between the services themselves? Are these comparable groups in terms of age, economic level, cultural background, marital status, and so forth? The second question is more difficult to answer. Are these social caseworkers and their practices comparable so that they are using similar bases for their impressions? If comparability in the area of the workers' competence and function, as well as in the groups of patients, is found, then they may proceed to formulate researchable theory which might well form the basis for profound study.

If a social service department has the philosophy that one of its basic functions is to contribute to the understanding of human behavior, and if it is willing to utilize research consultation in developing methods of recording, comparing, and testing observations, there is, I believe, no end to the potentialities for defining theory that can be tested by professional researchers.

Chronically ill persons will be well and fully served by caseworkers who neither seek nor need evidence of human suffering to justify their practice, but who will tolerate the impact of suffering because they have discovered the full significance of the difference their service makes now and in the future. I believe caseworkers can be helped to do this by sound supervision, thoughtful personnel management, and a broadening concept of their responsibility and opportunity in community planning and research.

The Nurse



The nurse contributes to the prevention of chronic illness through the care of patients during sickness. She also has a place in the prevention and control of communicable diseases which may of themselves be chronic or may lead to chronic conditions. It is often the nurse who carries out or assists others to carry out those techniques, in the hospital, the home, or the community, which limit or prevent the transmission of disease. She participates in case-finding programs and in the supervision of patients and contacts, helping to arrange for care as necessary.

The public health nurse is in a strategic position to observe family members, since she is a frequent visitor into many homes. She also often has health problems brought to her attention from many other sources. She may recognize the warning signals of such diseases as cancer, tuberculosis, or mental illness and encourage those in need to seek medical advice. The school nurse, the industrial nurse, the nurse in the physician's office, and the nurse in the outpatient service all have numerous opportunities to participate in accident prevention, health education, and care designed to prevent or minimize handicaps or chronic illnesses.

The effectiveness with which nurses meet their responsibilities to persons with chronic illness, as well as to others, depends largely upon the quality of their preparation and experience. We agree that every nurse should first be an expert practitioner of nursing, but we recognize that nursing now embraces a much broader field of service than it once did. Nurses must be prepared to care for the sick, but they must also be prepared to instruct and supervise patients and their families in various aspects of prevention and health care. They are expected to contribute to the nursing services of

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many types of agencies. They are called upon to plan for the nursing care of patients, to give some or all of that care, and to instruct and supervise others in giving nursing care.

Major Problems

The major concerns in nursing are the augmentation of nursing services and the improved preparation of nurses. In many respects these are interdependent. It is difficult to prepare nurses better in situations where nursing is narrowly conceived or of limited quality, and the betterment of such situations depends largely upon the availability of better prepared nursing personnel. Difficulties in obtaining the services of graduate nurses for chronically ill patients are due in part to the fact that there are not enough nurses to fill every need. However, they are due also to the fact that given a choice of opportunities for service, nurses will usually choose to work in situations that provide both security and satisfaction. These are sometimes lacking in the care of chronically ill patients. Reasons for this can be sought both in the preparation of nurses and in the situations providing care for patients with chronic illness.

When students are prepared in situations where nursing functions are almost exclusively viewed as providing physical care for sick patients in bed and where much of this care is provided by the students themselves, it is understandable that only limited background may be procured in psychology, sociology, psychiatry, and the other disciplines that contribute to effective relationships with people in a diversity of circumstances. The interrelation of emotional and social problems to health may receive little emphasis. The broad range of nursing functions may not be examined, and the students therefore may find it difficult to identify their role in analyzing patients' nursing needs or to plan with others to see that the total needs are met. Patient assignments are often so large that the students cannot get to know their patients well enough to identify their needs. In this situation, there can be little opportunity for patient or family teaching, or little chance to plan and work cooperatively with members of other health disciplines in providing comprehensive care for patients.

Thus, satisfactions are often obtained from the volume of the work done rather than from the quality of care and of the relationships that are established with patients and co-workers.

If a graduate nurse is not skillful in interpersonal relationships and is caring for a long-term patient, the frictions that may exist between them in January can be much accentuated by May. This usually troubles the nurse profoundly, since she may have been made to feel that in any and all circumstances a nurse should be able to adjust to any patient and to any situation. She does not look around her to see what factors have conspired to perpetuate the problem, nor does she have help available in studying the difficulty and planning for its improvement. In a word, her preparation for this kind of nursing has not been adequate, and she therefore rejects the experience, often seeking someone to blame rather than seeking solutions.

Psychiatric Experience

The field of psychiatry provides a striking example of the cyclic nature of the difficulties. Over 50 percent of the hospitalized patients in the country have mental illness, yet only between 3 percent and 5 percent of the graduate nurses working in hospitals are now employed in psychiatric facilities, whereas 48.7 percent of the country's 334,733 active nurses work in hospitals or other institutions. As recently as 1943, only 54 percent of the basic schools of nursing offered experience in psychiatric nursing to their students. However, since that date efforts have been made to have this experience included in the preparation of all nurses, and today over 90 percent of the 1,148 basic schools provide this experience. The number of nurses practicing in psychiatry has increased dramatically percentagewise, but it is still far from adequate. There are approximately 10,000 nurses and 80,000 attendants for some 700,000 hospitalized mental patients.

If students receive their basic preparation in a psychiatric facility where the patients number in the thousands but the total number of graduate nurses can be remembered by name, is it likely that they will be attracted into the field of psychiatric nursing? What is being

done about this situation? First, efforts are being made to have psychiatric nursing experience in basic schools looked upon as preparation for beginning positions in the specialty rather than as experience which will improve understanding in any nursing position, a viewpoint which was publicized earlier to make the experience more palatable in the eyes of the students and their families. Second, mental health principles are being integrated throughout nursing curriculums, and work is going forward in many schools to strengthen and broaden the psychiatric nursing experience per se. The division of nursing education of the National League for Nursing is working with nursing schools throughout the country in self-evaluation and improvement in psychiatric education, as well as in other aspects of their educational programs, and organized nursing is beginning to coordinate its efforts with such groups as the American Psychiatric Association for improving nursing services in psychiatric hospitals.

Membership and participation in the National League for Nursing and affiliated State and local leagues provide opportunities for consumers of nursing service, members of allied professional groups, and nurses from many fields of nursing to plan and work together to improve nursing services wherever necessary.

The Welfare Worker



Positive approaches to persons with chronic illness are of inestimable importance in public assistance programs if their basic purpose—the conservation of human resources and providing the opportunity for a useful life—is to be

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achieved. The groups served under Federal-State assistance legislation—the aged, the blind, the permanently and totally disabled, and the families in which children are deprived of parental support or care by reason of the physical or mental incapacity of a parent—are the groups in which the incidence of chronic illness is high.

In public assistance agencies, more than 80 percent of staff has no training in social work. In this 80 percent are workers, supervisors, and administrative personnel. They bring to the job all the attitudes toward illness encountered among the public.

I shall limit my discussion to the problems of public assistance workers in their relationships with the medical profession and the effect of agency structure, policy, and procedures on the workers' relationships with chronically ill persons. Experience with incapacitated parents and the permanently and totally disabled is especially pertinent. Many of the persons involved are still in their productive years; therefore, the possibility of social usefulness or the return to economic independence is present. Most recipients in these two categories live in a family group. Relieving, to the extent possible, the ill effects of long-term illness on wholesome family life is another important end toward which public assistance workers must strive. Consideration must be given to the role, responsibilities, feelings, goals, and potentialities of all of the members of the patient-recipient group.

Physician-Worker Relationship

The proper approach to establishing eligibility when illness is a factor is not only establishing that the individual is ill, but also determining what can be done to enable him to mobilize himself and what resources are available to him so that his capacities are released for the solution of his own problems. In general, public assistance workers have received their equivalent of "medical information for social workers" through experience. This is to say, it has been gathered from many and devious sources in varying degrees of reliability: personal experience, friends, spasmodic or continuing contacts with physicians and health

facilities and agencies. These condition the physician-worker relationship.

A basic major problem in this relationship is the failure of public assistance workers to see the commonness of interest they have with physicians in the recipient-patient. Too many still think of the physician as an unapproachable person, preoccupied with epilepsy, arthritis and cortisone, cancer and surgery or radium, and do not realize that his focus is on people who have disease. They expect him to be all-knowing and infallible. Consequently, they believe that what they know about the recipient is either already known to the physician or will contribute nothing to the treatment plan. Although they must depend on the physician to interpret illness to them, they do not assume responsibility for interpreting assistance to the physician.

With the establishment of the category of aid for the permanently and totally disabled, despite the negative connotations, public assistance agencies have made some strides toward improving physician-worker relationships. A major contribution was made by having at least one medical consultant on the State agency's staff. This consultant, who is part of the physician-social-worker team, is oriented to the agency, its needs, and its purposes. He is expected not only to review cases, but also to help the agency devise policies and procedures which serve the agency's purposes and are acceptable and understandable to the medical profession. Although the public assistance worker may not have direct access to the medical consultant, he is at least aware that it is possible for a social worker and a physician to communicate, and that each can contribute to the helpfulness of the other.

Agency Policy and Procedure

In administration, there is much recognition of the worker as the one who carries out the purpose of the agency. There is less expressed cognizance of the influence agency policy and procedure have on the way a worker can carry out that purpose. Public assistance agencies have a serious responsibility for reviewing policies and procedures as a whole, not just those related to health care, for the effects they have

on workers' attitudes toward chronically ill persons. All agency policies should encourage the sick to seek and respond to treatment, maintain health which is restored, and use their own resources with the supportive help of the agency in managing their own affairs to the maximum extent possible.

Policies and procedures completely divorced from health care can create extremely negative results for persons with chronic illness. To illustrate, I am reminded of a family of three in which the father—Mr. Allen, I shall call him—was under care for a chronic cardiac condition. He had managed and supported his family long after his physician had advised him against working in the steel mill. When he could no longer do the work his job required, he applied for and received assistance. He was described by many public assistance workers over a 2-year period as cantankerous, demanding, and uncooperative, but one finally found a way to work with him. She was very sensitive to his need to provide for his family. She talked with his physician about this need and asked him how his heart condition affected the feasibility of vocational rehabilitation. She was told Mr. Allen's activity limitations and that she might do well to discuss with the recipient how he felt about it. Mr. Allen at first said he didn't want anything but his check, but after about three visits from the worker he went to the rehabilitation office to explore what they had to offer. Eventually, he decided upon a course in barbering. He made excellent progress and was enthusiastically sharing with the worker his high hopes for employment.

About this time, the agency issued a policy that required all able-bodied mothers with only one child of school age to take available work within a given time period or assistance would be withdrawn. Mrs. Allen was a docile person whose dependency on her husband was as important to him as to herself. She had not worked since she married, but she took a job as bus girl in a diner on the highway about a mile from home. Her earnings were inadequate so the family received supplementary assistance. One day Mr. Allen's physician called the office to ask what had gone wrong. For three nights

in a row he had had to treat Mr. Allen for serious heart attacks. In addition, Mrs. Allen had a bad chest cold. The worker went to see the family immediately. Mr. Allen propped himself up in bed and summoned all of his energy to give the worker a piece of his mind.

The worker was able to discern that this man's problem was his wife's employment, which he viewed as a threat to the assumption and maintenance of his role as head of the household. Mrs. Allen was reacting to having to assume a leadership role which she did not want. The acute exacerbation of Mr. Allen's chronic illness meant that his wife had to stay at home to care for him. How soon he would go back to his training course was uncertain. Additional money was paid to the family because of increased medical expense. The policy about women with only one child accepting employment sounded so simple!

Summary

Physician-worker relationships and agency policy are two areas which can give rise to positive or negative approaches to the chronically ill. Sufficient trained staff under skilled supervision would be ideal, but the day when this can be achieved in public assistance programs is not within the foreseeable future. For the staff now employed, opportunities for educational programs which have content on concepts of disease and the meaning of illness should be developed or strengthened by public assistance agencies. As workers learn about the dynamics and defenses in illness, they will be better able to collaborate with the physician as a positive influence in the lives of people who, though disabled by illness, still strive toward survival and satisfaction.

No matter how adequately trained the staff is, unless the agency affords a climate in which constructive help can be given, the worker cannot help. Policies are the interpretation of the intent and purpose of legislation. They should be looked at in terms of what they do to people as well as what they do for people. The test of any public welfare program is its advancement of individual human welfare.

The Volunteer

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brief

Successful rehabilitation for any individual depends on three things: the attitude of the general public; the attitude of the patient himself toward his chronic illness; and, facilities for care and treatment which the community provides. If the general public, which includes the volunteer, believes that every person, regardless of what has happened to him physically, mentally, or socially, is still an individual member of the community, there will be certain universal convictions. Such convictions will include the belief that a chronically ill person must be given the opportunity to develop to the fullest all his capacities, many of which may be hidden or undeveloped, as well as treatment for whatever the disability may be. This attitude of the public will often be reflected in the attitude of the patient toward his situation. This attitude of people with whom the patient comes in contact, whether it be the neighbor who brings in the bowl of soup, the relatives who sacrifice personal desires to be of service, or the professional visiting nurse or social worker, helps the patient retain pride in himself even though he faces tremendous obstacles and even when he recognizes that there is no hope for physical recovery.

Two Groups

I should like to discuss volunteers in two groups. The first includes those who do things on their own and as they see them. These volunteers have innumerable contacts with patients who are chronically ill, and their own attitudes help to influence the patient's attitude toward his disability, his family, and

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his community. One patient with chronic illness told me once, "I do like Mrs. — from our church, but honestly, she practically buries me every time she comes." Or, another, "I do like Mrs. —, but really I cannot stand to hear her problems, and she talks so much." Reaching these volunteers is difficult, but usually they can be reached indirectly through groups of which they are members. Some, of course, are never reached, and go on in their own way.

The second group of volunteers are those who are recruited and trained for specific work and who serve a specific organization. Volunteers in this group either wish to give direct service to a patient—occupational therapy aides, home visitors, and ward aides in hospitals, for example—or to work for a cause which will benefit a patient without coming in contact with him—attendants in waiting rooms, bandage makers, and solicitors for funds. Both of these groups are dedicated to a purpose and both are responsible for creating public opinion. It is a wise organization or agency which recognizes that the volunteer in each group is deeply concerned about someone. Often, what happens to the individual for whom an agency exists is based on the emotions, the knowledge, and the ability of the volunteer. Thoughtful decisions, wonderful plans, beautiful outlines made in high places, like this meeting today, won't make life more livable for Mary Jones, a 35-year-old cancer patient now in a county home with nothing to do, until volunteers of that community decide what they want for persons with chronic illness.

Knowledge Requirements

All volunteers should be well informed about the causes which they serve. Also, they should be given information, from authoritative sources, on the disease itself, the resulting disability, possibilities for rehabilitation, facilities for care, and what is being done and not being done in research or prevention. If the volunteers are giving direct service to patients, they should be told as much as feasible about the plan for the particular patient. The volunteers should understand that most members of the family are bewildered when a chronic illness

occurs. They should understand the responsibilities of government agencies as well as the responsibilities of all the various private agencies.

All volunteers giving direct service to a patient should be given not only general information but also specific training for the particular service they are to provide. As a rule, volunteers respect training courses and are eager for continued training after they accept an assignment. The attitude of a volunteer toward his particular assignment is often conditioned by the respect which the professional worker or the agency shows for the volunteer service.

In addition to the specific training for ward duty, occupational therapy, or friendly home visiting, the volunteer must understand the implications of the particular chronic illness. For example, a patient should not be considered "stubborn" or "ornery" when his attitude is just as much a part of the chronic illness as is

the paralysis, for example. A volunteer should also have easy access to a professional worker who can help the volunteer understand some of the problems which arise.

The intelligent volunteer appreciates his own services. He knows that more and more volunteers are needed. He lives his philosophy, day in and day out. He participates actively in supporting legislation and in backing adequate finances for both government and private agencies. He is eager for research, and he urges an educational program which has prevention as its aim. He recognizes the need of professional staff and never doubts the teamwork of the volunteer and the professional worker. He will recruit staff. He will fight for adequate facilities. The volunteer is the strength behind the health and welfare programs of our country. The professional workers have a definite responsibility in keeping volunteers in step with all the advances in health and welfare.

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